
Consumer Action in Health Care

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The past and present of the consumer movement in health care, modes of consumer participation, and issues concerning consumer representation on State regulatory boards for the health professions

IN THE WORDS OF GEORGE BERNARD SHAW, "Every profession is a conspiracy against the public." Correct or not, this statement is a topic of continuous debate and the subject of numerous articles and books. The health professions are not immune to this charge, and there is no question that changes in organization and financing of health care, rapidly advancing technology, and increasing consumer demands will have a substantial impact upon the future practice and stature of the health professions. Yet many health professionals are not aware of, are immune to, or are unable to cope with these forces.

Consumers are reacting to the high costs of medical care—hospital care, physicians' services, drugs, and the like—and are beginning to express dissatisfaction with traditional modes of health care practice. Various groups representing consumers are demanding more openness and greater competition among providers of services, with the result, for example, that the Supreme Court has recently acted to remove State restrictions on advertising prescription drugs. There have also been considerable pressures, on behalf of consumers and health professionals alike, to allow supervised paraprofessional technicians to perform routine health care tasks in order to lower service costs. Finally, consumer

groups are demanding and receiving a greater voice in the governing affairs of State boards that regulate the health professions. At present, 12 States require consumer membership on one or more regulatory boards (medicine, pharmacy, or nursing), and in 20 or so other States, legislatures are contemplating such a requirement. Some health professionals regard consumer participation in standard setting as unfair, unduly restrictive, and an inappropriate and dangerous erosion of their professional rights and prerogatives. A common response is a reactionary one: that the problems being addressed are not substantial or that some other group in the health care area is more worthy of challenge.

Historical Background

Americans have a long history of speaking out whenever they perceive that decision-making processes are not fully representing their interests. The American Revolution, the Civil War, labor unrest during the depression years, the civil rights movement of the 1960s, and the Partnership for Health Act of 1966 are examples. The transition from a participatory democracy, as exemplified by the town meeting, to a more manageable representative democracy as governing bodies became larger increased the likelihood that some consumer constituencies would not be adequately represented. The contemporary demand by consumers for community participation and control may be viewed as a logical response to a perceived growing impersonality and lack of responsiveness of large governmental and social service systems (1).

The consumer movement of the 1970s can be seen as an outgrowth of the 1960s, a period marked by challenges to existing social institutions and mores.

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Also challenged in that period was the traditional paternalistic and authoritarian relationship between the professional and the client. McCormack (2) has suggested that such challenges, in turn, may be the inevitable consequence of the professionalization of occupations in the 1950s. In the process of becoming professionalized, the occupations became more specialized, more self-governed, and more nearly autonomous. Consequently, they became less "other" (client) governed and less subject to public accountability or control. McCormack described this as an unbalanced and untenable situation which inevitably had to be corrected. A major lesson learned from such challenges is that they can produce positive responses from social agencies.

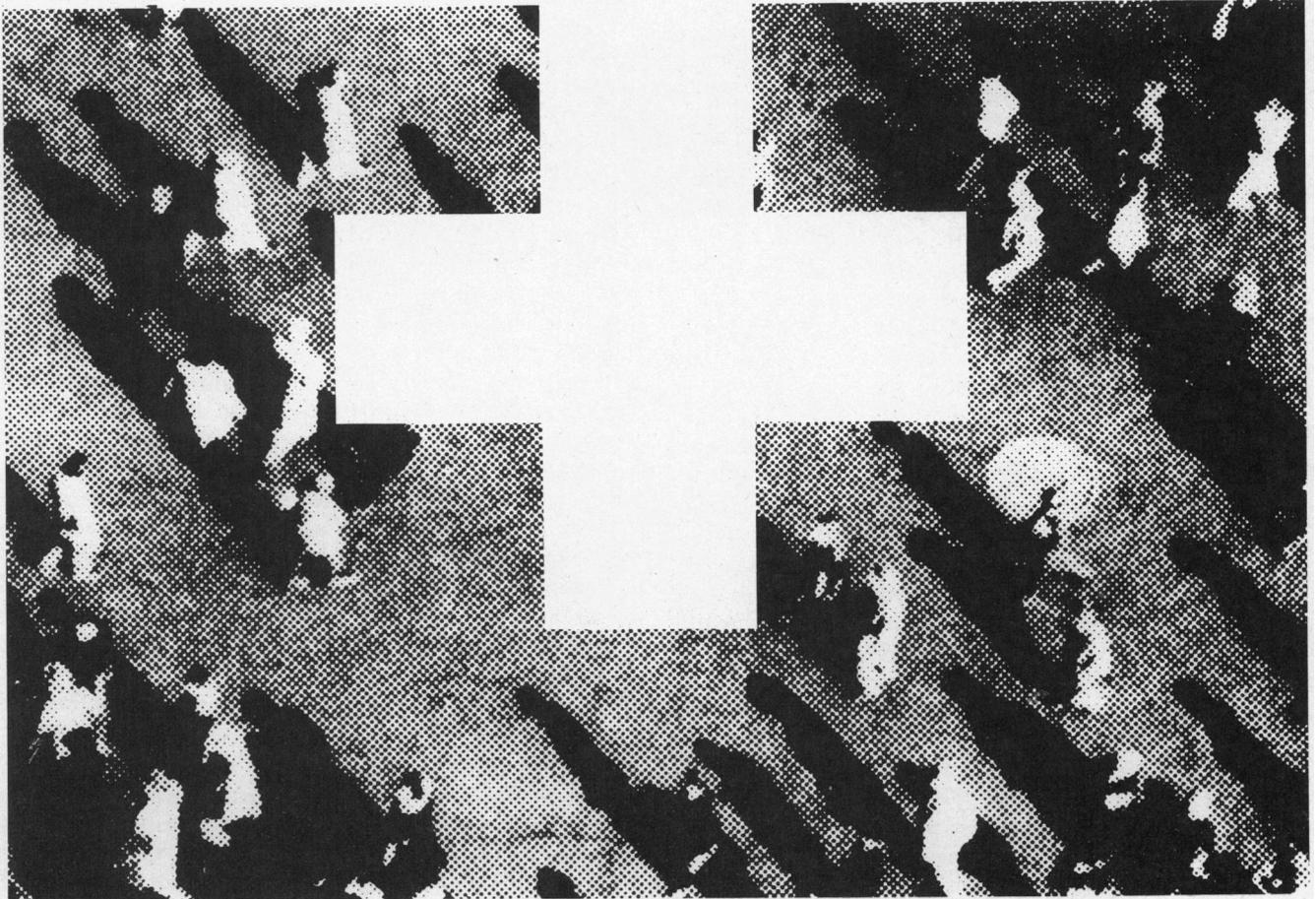
With respect to health care, other more basic factors have contributed to increasing consumer demands for public accountability, participation, and control. Consumers have become better educated and more sophisticated about health care. As they have come to accept the inevitability of modern medical cures, their health care expectations have risen markedly. These expectations, however, contrast with substantial problems related to the delivery of medical care. It is well known that, although our medical institutions are capable of providing the finest medical care in the world, the care

received by large groups of citizens is episodic, crisis oriented, and costly to the point of being catastrophic to family finances. Often medical care is not accessible at all to certain groups. For the past few years, consumers have been saying that the present situation is intolerable, and that medical care institutions and health professionals must be held accountable for their actions.

Modes of Consumer Action

Consumers have several mechanisms available for making social institutions or markets more responsive to their demands. One is economic control through refusal to purchase—the option to exit from the marketplace. When this mechanism falters, the trend has been to turn to other processes, such as collective control of funds (third parties) or legislation.

Exercise of their sovereignty in the marketplace is the traditional mechanism used by consumers, individually and collectively, to assure adequacy and availability of services. However, in the medical services market, this approach has been only marginally successful (3). One reason relates to the economic concept of need versus demand and the consequences of the consumer's uncertainty about the medical service product. Despite becoming increasingly knowledgeable and sophisticated,



consumers are hardly experts in evaluating medical services, or even in selecting the services appropriate to their needs. Traditionally, the health professional determines need, and redefines demand, for services on behalf of the patient. There is ample evidence that consumers choose medical practitioners on the basis of nonmedical rationale, and that when consumers become patients, professional prerogatives predominate (4).

Exercise of sovereignty rights has also failed to control medical markets because large groups of consumers have encountered difficulties in attaining access to the medical care market, or have actually been denied access, because of geographic, economic, or ethnocultural barriers. An undersupply, or more accurately a maldistribution, of medical care facilities and practitioners, together with substantial barriers to entry, tends to deter market responsiveness to consumer preferences or demands.

Finally, the very nature of illness militates against a powerful role for the consumer in exercising his right of refusal or his right to go elsewhere in the medical market. The ill consumer does not feel good and often wants or needs immediate care, a condition making the alternative of seeking services elsewhere extremely unattractive, or even impossible.

The consequences of individual and collective assertions of control by consumers can be seen in the market for some health-related products, most notably prescriptions and eyeglasses. Although consumers may not know the exact nature of the product, they generally do know, for example, that prescription drugs from various sources are similar, and they respond by basing decisions to purchase on cost and geographic or time convenience (5,6). The rapid proliferation of pharmacy departments in large chainstores across the nation reflects the buying preferences of consumers (7).

Consumers must explore other means of eliciting medical market responsiveness when the exit option fails. One alternative is to become a more sophisticated consumer of health services by becoming better informed about common indexes of practitioner and service quality, service fees, and patients' rights. Consumer guides to physician and hospital services have been developed in several communities for this specific purpose. Consumer sovereignty may also be strengthened through further development and exercise of informed consent provisions in State laws. Stevens (3) argues that the concept of informed consent should be expanded to include full disclosure of the therapeutic situation by the practitioner. This would allow the patient to become an active participant in the therapeutic decision and would thereby help to prevent poor medical practice and unnecessary medical treatment. Achievement of these objectives, however, may be difficult for the consumer. To supplement individual efforts, Stevens also advocates collective consumer representation, through a lay manager role, as a vehicle for exercising constraint on health practitioner sovereignty.

Activities of consumer representatives might include participation on utilization review or grievance committees, development of performance standards for practitioners, and formation of health care policy.

Evidence of increasing consumer strength in the health sector can be seen in the growth of health and welfare programs for labor and of consumer "cause" groups such as Ralph Nader's public interest research groups, women voters, Consumers Union, and senior citizens. These groups have been somewhat successful in exerting pressure through the marketplace and, increasingly, through representative participation in health care systems management.

Third-party payment plans are also a means of representing the collective interests of consumers. Control over health care providers has been exercised primarily through control of financing, and has been extended to quality assurance and accessibility and availability of services. Third-party payment plans vary, however, in composition, sponsorship, and effectiveness. Historically, the nature of sponsorship has tended to be the best indicator of whose interests are most protected. Provider-sponsored Blue Cross and Blue Shield plans are cases in point. Nevertheless, organized consumer representation, through control of financing, is a potentially powerful mechanism for exercising constraint on health practitioner sovereignty.

Additionally, the collective voice of consumers has been effective in implementing change through legislation. Consumers or their advocates have contributed substantially in securing passage of several laws designed to alleviate inequities in the health care system. The Economic Opportunity Act of 1964, the Partnership for Health Act of 1966, the Medicare and Medicaid amendments to the Social Security Act, and the National Health Planning and Resources Development Act of 1974 are examples.

In addition to providing health care to needy constituencies, these laws introduced a new method of social control by requiring consumer participation or direct public accountability mechanisms, or both, as a prerequisite for participation in and receipt of financial support from Federal programs. One of the most notable is the Partnership for Health Act of 1966, which provided for the creation of local comprehensive planning agencies ("b" agencies) charged with the task of planning allocation of health facility resources. To assure local determination and citizen input, local citizens must comprise at least 51 percent of the membership of the board of any of these agencies. Also notable was the Economic Opportunity Act of 1964, the guidelines of which called for maximum feasible participation for the poor in most social programs, including health.

In neither of these programs, however, has the mechanism for consumer participation been particularly successful. Although the reasons are complex, the major problems appear to be (a) lack of sufficient

governmental planning and policy formation for this new type of endeavor, (b) lack of clarity at all levels in policy implementation, and (c) local political pressures resulting from perceived threats to the established power structure (1).

Reaffirmation of the principle of consumer participation and involvement was provided by the Task Force Report on Medicaid and Related Programs (8), which stated that “. . . greater consumer involvement in decision making is required to overcome deficiencies in the health care system . . . and to achieve better management of resources.”

The latest and perhaps most significant health legislation involving consumers is the National Health Planning and Resources Development Act of 1974. This act, which, in effect, supplants two previous health planning programs—the regional medical programs and the comprehensive health planning program—creates a network of local agencies responsible for health planning and development. Of significance for consumers is that the board which directs the activities of the local health planning agency must be composed of at least 51 percent consumers. Thus, although consumer participation has not always been effective in the past, the national commitment to the concept has been reaffirmed.

Representation on Regulatory Boards

Despite difficulties in implementing requirements for consumer participation, pressures for public accountability in the health sector remain strong. The growing demand for consumer representation on health professional regulatory boards is a case in point.

A recent report from the Department of Health, Education, and Welfare (9) reflects this public concern, stating, “There is growing public sentiment that membership on licensure boards should not be limited to the licensed profession.” California is often cited as a pioneer in this regard. It has required a public member on its health professional boards since 1961 and has recently increased the number to two members on some boards.

Health authorities and members of the health professions have also advocated public representation. Selden (10), for example, has suggested that the addition of public members to licensing boards would provide greater and more consistent assurance that the public welfare is the overriding criterion on which decisions are made. Another government report (11) has recommended that boards include members representative of consumers, other health professions, various methods of health care delivery such as group practice and public institutions, educators, and others in policymaking positions in health care.

Advocates of consumer representation on regulatory boards offer several arguments in its favor. They point out, for example, that if the board is doing an acceptable job, it should have nothing to fear or hide from

the public member. Advocates also claim that the public member can add fresh insight and orientation based on the public welfare as the essential criterion. Finally, they maintain that consumer representation provides the board with the rudiments of public accountability and legitimizes the board's stated purpose, thus broadening its power base and areas of decision making.

Consumer participation, however, has not gone unopposed; in fact, substantial controversy exists. Opponents of public membership claim that nonprofessionals cannot understand board activities since they do not understand or have the knowledge of practice needed to serve on a board. Others assert that consumers will only interfere with normal business activities of boards. Still others ask who the public members represent and question their purpose in seeking membership on health professional boards.

There is to date no indication that consumer representation on regulatory boards will be any more effective than the Office of Economic Opportunity or Partnership for Health programs in assuring responsiveness to consumers. The experiences of these programs (if indeed they can be generalized to this situation) suggest that the passage of legislation merely requiring public members on boards may not be enough to assure achievement of stated objectives.

The DHEW report on health manpower licensure concluded, on the basis of California's experience, that placing public members on licensing boards provides no danger of disruption of board functioning (9). On the other hand, the report stated:

. . . the degree to which the addition of public members has resulted in greater public accountability—as opposed to the narrow interests of a particular profession—is open to question. Of course, the very presence of lay members has probably tended to open up some of the secrecy attending board policymaking, but whether this is the sole function of public representation needs to be addressed, for the danger of token accountability lies in a facade of public reassurance, while permitting past practices to continue unabated.

One aspect of this public accountability that needs to be addressed is whether or not the method of placing members on boards could be improved. Most statutes add public members to the boards, rather than replacing a position previously filled by a professional. Some statutes have also provided for an additional professional member when a public member was to be added. Moreover, because many statutes require professional board members to be selected from a list provided by the organization of professionals being regulated, the public member may have little opportunity to influence the other members.

Cohen (12) cites the recent flurry of bills which provide for consumer representation on licensing boards and raises several important, but often overlooked, issues. He questions the autonomy of the appointed public members, the extent to which public members are permitted to challenge decisions made by professional members of the boards, and the extent to which they accept responsibility for challenging such deci-

sions. He is also concerned about the availability of an organized constituency, or power base, from which the public members can exert leverage on other board members when they feel that the board is not acting in the public interest.

As if they anticipated these questions and concern, Shimberg and colleagues (13) proposed that licensing boards include a technically competent representative of a State government agency instead of a nonprofessional public member.

Problems in Implementation

Consumer participation in regulatory actions can range from membership on advisory panels, to ex officio membership on boards, to full membership. Full membership would appear to be the best mechanism for assuring consumer contributions to decision making, but it does not assure active participation in the board's decision-making processes.

Kosa and co-workers (14) discuss three alternative versions of participatory democracy for consumers who are members of regulatory boards:

1. Containment: confining decision making by consumers to minor issues.
2. Co-optation: influencing consumers to support and vote for the majority or elitist position.
3. Co-determination: self-interested and self-determined action of the consumer.

Co-determination is obviously the goal, but it is often difficult to achieve. From analysis of attempts at participatory democracy in the antipoverty programs of the 1960s, for example, Kosa indicates that co-optation was the predominant mode, that containment was practiced but fell into decline as less useful, and that seldom was anything approaching co-determination accomplished.

Major problems remain in assuring that consumers not only attain active membership status, but that they also assume an active participatory role and thereby assure public accountability.

The public member must not only be representative, but he also must maintain communication to and from his constituency. Usually, however, the constituency that the consumer is expected to represent is not explicitly defined. Often initial appointments of consumers to board membership are made by State Governors on the basis of friendships or social position in the community. Such persons may represent only small, albeit important, constituencies, such as the business community, a particular social class, or a particular political party. As a result, major consumer groups remain unrepresented, and the board may not receive any input from these groups.

Co-determination is difficult to achieve even under the best circumstances. The consumer representative is initially highly uninformed about many of the technical aspects of professional practice which take up much of board meeting agendas. As a result, the repre-

sentative is learning during much of his tenure, and he may not become an effective participant until his term is about to expire. A major related question is: Should consumer representatives be allowed to participate as fully active, voting members on all board affairs, or only on consumer-oriented issues? If the consumer representative remains on the board for a long time, on the other hand, another problem arises. During the process of learning intimate aspects of the board's functions, the consumer may change his attitudes, beliefs, and advocacy positions, so that he no longer represents the views of his constituency, and in fact becomes a highly trained, but now unrepresentative, board member. The Task Force on Medicaid and Related Programs (8) seemed to recognize some of these problems in calling for representation of broad as well as particular consumer interests.

Galiher and colleagues (15) have considered some of the problems associated with making consumer participation truly effective. They suggest "a planned system of producing informed consumers chosen from all those who are served, phased through a series of experiences on varying levels. . . ." Through this process, consumer leaders with the most to contribute and the most personal charisma would emerge. These leaders would then be qualified to affect directly decisions and health care outcomes.

Summary and Conclusions

The responsiveness of the health care market to consumer pressures for change and more accountability has been less than optimal. One reason is that the traditional mechanism employed by consumers to evoke market responsiveness—the refusal to purchase—has been largely ineffective in influencing health care delivery. As a result, alternate strategies such as collective consumer representation through third-party payment programs, control through legislation, and demands for consumer participation in health care policy making have been used.

Most notable in recent years have been the increasing demands by consumers for greater public accountability and control of regulatory boards, as evidenced by legislation to permit consumer members on these boards in several States. For consumer representatives to be effective in influencing actions of the regulatory boards, however, mechanisms must be developed to encourage their active participation.

This demand for greater public accountability of regulatory boards should not be viewed negatively, but rather as an opportunity for the boards to develop new and more viable roles. Cohen and Miike (16) suggest, for example, that the public accountability obligation of licensure boards embrace a broader responsibility for quality assurance, involving public representation in the process.

Major problems remain as to how best to obtain greater public accountability, responsibility, and con-

trol. The position of the public member with respect to the regulatory board—that is, on an advisory panel, as an ex officio member, or as a full member—has been determined by legislation, but little attention has been devoted to means of assuring that consumer representatives are active, and interactive, participants. Resolving this difficulty is the first step toward achieving greater social accountability and a more viable role for regulatory boards governing the health professions.

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THE ISSUES, IN BRIEF

HEALTH CARE has always been a matter of choosing among alternatives. In the past, the choices were made by health care providers alone, the assumption being that the choices were purely medical decisions. We are now accepting the notion that not all choices are that clearcut—that they often combine medical with nonmedical, usually economic, considerations. Obvious current examples are generic versus trade name drugs, optometrist versus ophthalmologist, internist versus family physician versus paraprofessional. These examples show that the debate is not simply between providers and consumers, but also between health professions, within health professions, and between traditional and new modes of delivering care.

What should the role of the consumer be? The answer is relatively easy in certain situations. In providing health care for specific populations, the representative's interests are usually identical to the interests of the patient population served. This is seen clearly in negotiations between labor unions and organized professional services for the provision of health care.

The consumer's role is nearly as clearly defined for ombudsman programs in hospitals. But in decision making on broader policy matters, as exemplified by the actions of regulatory boards, the aims are more diffuse and consumer interests more numerous and varied. Representation on regulatory boards does not necessarily mean that input from consumers should or will be equal in all decision making. It does, however, indicate recognition that there are board functions that may not require specific professional knowledge—that may, in fact, be better decided by nonprofessionals. Ethical issues and who should decide them are undergoing similar changes.

In summary, two facts are evident: board functions are changing and consumer input is one of these changes. However, the interests of the consumer are difficult to identify with any degree of consistency and broad applicability.

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